

Name: Franco Sicuro | [REDACTED] | PCP: Dion G. Fisher, MD

Appointment Details

Notes

Progress Notes

Amber Marie Malcolm at 8/4/2021 12:07 PM

Patient Name: FRANCO SICURO

Encounter Date: 8/4/2021

ALS Follow Up Note

Franco Sicuro is a 66 y.o. male seen today at the Washington University Neuromuscular Clinic for follow up for his amyotrophic lateral sclerosis.

Neuromuscular Attending: Al-Lozi

ALS Onset: June 2019- left leg cramps followed by weakness/ he noted he could not stand on the left leg.

ALS Diagnosis: October 12, 2020, with a presumptive diagnosis after EMG in August of 2020.

EMG: August 25, 2020 at WUSM: Yes

EMG Results: *Widespread denervation in three body regions with fasciculation potentials in the deltoid and vastus medialis. In the presence of relatively preserved SNAPs, these abnormalities are consistent with diffuse anterior horn cell disease such ALS or multiple level polyradiculopathy. There are no conduction blocks in this study to support multifocal motor neuropathy. Note, however, that these abnormalities are non-specific and should be interpreted in the context of the clinical presentation.*

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Discussed this visit: home suction machine, cough assist device , and percussion vest.

EXHIBIT D

Willing to obtain after today's discussion: He is considering home suction machine, cough assist and percussion vest.

[REDACTED]

He was last seen in clinic by Dr. Al-Lozi on February 4, 2021.

Since his last visit in clinic he has noticed that walking has gotten harder. **He walks longer distances with his wife.** He feels that he leans forward too much when walking and tries to correct by leaning back more which also make him feel unsteady.

He recently was able to start NIV with a Trilogy ventilator and that has improved his sleep and how he is feeling. He slept 8 or 9 hours the first night. He is not using it during the day though he does admit that he sometimes feels short of breath through out the day with activity or doing a lot of talking. During the first hour he has trouble coughing. He does not currently have a home suction machine or cough assist or percussion vest.

He has some back pain and pain and cramping in his fingers and toes. Uses massage gun on ribs and other muscles for cramps. He is not on any muscle relaxers.

Currently he is not using any durable medical equipment at home aside from an AFO and his Trilogy ventilator.

He denies any weight loss or trouble with eating or swallowing. He does admit that only mildly spicy food even only black pepper of any kind triggers a cough. Ends up drinking water with each bite of food at times.

He reports changes with his speech. Had to clear throat a lot prior to Trilogy. Trouble getting through a sentences without SOB.

He denies any sialorrhea. He has some dry mouth which has improved a little since the initiation of his NIV.

He denies any falls since his last clinic visit.

[REDACTED]

[REDACTED]

[REDACTED]

Current Outpatient Medications

Medication	Sig	Dispense	Refill
• cholecalciferol (VITAMIN D-3) 5,000 unit capsule	Take 5,000 Units by mouth once a week		
• pantoprazole DR (PROTONIX) 20 mg EC tablet	Take 20 mg by mouth daily		

[REDACTED]

[REDACTED]

[REDACTED]

Vital Signs:

There were no vitals filed for this visit.

ROS:

A complete review of systems was performed including constitutional symptoms, cardiovascular, respiratory, gastrointestinal, genitourinary, musculoskeletal, neurological, psychiatric, endocrine, immunologic, integumentary, hematological, eyes, and ears, nose, mouth, and throat. All systems were negative except as per HPI.

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Assessment and Plan:

Franco Sicuro is a 66 y.o. male with amyotrophic lateral sclerosis. Mr. Franco Sicuro is co-followed by me and Dr. Al-Lozi.

Dr. Sicuro has had progression of his ALS as expected. Today we talked about prognosis of his disease. Currently his forced vital capacity is slightly over 50% of predicted.

At this point I do expect him to have the typical course of ALS which leads to death within 2-5 years from symptom onset. He will also likely require constant daily care for all of his activities of daily living at some point within that time. The goal of ALS care is to follow up patient's prognosis and make recommendations and referrals as needed to meet their needs.

1). Mobility issues/ unsteady gait/ activity intolerance due to restrictive lung disease from ALS weakness.

- He is in need of a rollator to help with gait stability. We discussed his current gait issues as well as activity intolerance and that would be helpful for him.
- He becomes SOB with activity. Due to this issue he would benefit from a power wheelchair sooner rather than later. We briefly discussed the process of getting a power.

- Dr. Sicuro has ALS and at some point in the near future will likely be unable to functionally or safely ambulate due to disease progression and resultant muscle weakness. Currently his breathing difficulties limit his ability to walk longer distances without a break or without becoming short of breath. If he cannot ambulate safely, even with an assistive device (cane, walker, etc) due to progressive symptoms related to ALS he would then be in need of a custom power wheelchair.

- Dr. Sicuro also had questions about exercise in ALS. He feels as though he would like to try to be more physically active however he is not sure he will be able to accomplish this due to his ongoing shortness of breath. We discussed that moderate exercise in ALS is likely beneficial. If he is able to find a way to do a safe and comfortable exercise while using his NIV that may be one way that he could accomplish this goal. For example he maybe able to use a stationary recumbent bicycle if he uses his NIV during this time. He will reach out with any further questions.

- I put in a referral for him to see a physical therapist at the Rehab Institute at Saint Louis to further discuss these issues and for gait evaluation for more specific recommendations on physical activity and gait.

2). Dysarthria.

- I have discussed voice banking with Mr. Franco Sicuro. He we will have Carrie Mosley SLP at The Rehabilitation Institute of St. Louis reach out to him with further instruction on this process and to discuss the process of obtaining an augmentative communication device when needed.

3). Dysphagia.

- He reports only minimal symptoms with this at this time.
- We have discussed swallowing dysfunction in ALS generally and the fact that patients with ALS often have to make the decision of whether or not to get a feeding tube. Feeding tubes can be used as a supplement to oral intake or a person can take in all of their food and fluids through a feeding tube. He is not ready to make a decision on getting a feeding tube at this point but would consider it in the future if needed.

4). Respiratory secretions issues/ need for clearance device.

- He is having trouble clearing secretions due to a weak diaphragm. Franco Sicuro is in need of a cough assist device or a percussion vest to help clear secretions. I have sent him some information on those two devices and he will let us know if he would like us to order one or both of them to help with secretion clearance. He would also benefit from a home suction machine to help completely clear secretions. He would benefit from both a vast and cough assist device.

- He could also consider using some guaifenesin as needed to help loosen secretions which could be helpful to loosen mucus..

5) Treatment of ALS.

[REDACTED]

Today he will see our physical therapist to have an FVC preformed and discuss any mobility issues that he is having. He will also see the MDA and ALS Association representatives as well as our research coordinators.

My total encounter time on 8/4/2021 was 95 minutes which was spent in the activities documented in the note. This includes time spent prior to the visit and after the visit in direct care of the patient. This time does not include time spent in any separately reportable services.

I appreciated the opportunity to be involved in the care of Mr. Franco Sicuro. Please do not hesitate to call with any questions.

He will continue to see Dr. Al-Lozi and myself at least every 3 months or more often if needed due to ALS progression or symptom management issues.

No follow-ups on file.

Future Appointments

Date	Time	Provider	Department	Center
8/30/2021	11:00 AM	Hopfinger, Mary Rebecca, NP	NM CAM 6C	NL
9/16/2021	11:30 AM	Chi, Luqi, MD	SLEEP CTR 40	NL

Sincerely,



Amber Marie Malcolm, NP

Amber Marie Malcolm at 8/4/2021 12:07 PM

 **Washington University in St. Louis**
SCHOOL OF MEDICINE

DEPARTMENT OF NEUROLOGY
Neuromuscular

Letter of Medical Necessity for Non-Invasive Ventilation on Flight

August 4, 2021

Re: Franco Sicuro [REDACTED]

To Whom It May Concern:

Please be advised that Mr. Franco Sicuro is under the care of Dr. Al-Lozi and myself for Amyotrophic Lateral Sclerosis (ALS).

ALS is a progressive neuromuscular disease that causes profound muscle weakness and spasticity in all of the voluntary muscles of the body. This includes muscles used for breathing and swallowing.

As part of his care, Mr. Franco Sicuro is required to use non-invasive ventilation (known as BiPAP or AVAPS) intermittently to assist with his breathing. While medically appropriate for him to fly, it is essential that he travel with the BiPAP machine so that he can use the non-invasive ventilation during the flight, if needed for respiratory support.

Please do not hesitate to contact Dr. Al-Lozi or myself with any questions and/or concerns.

EXHIBIT D

In addition to the contact information below I can also be reached by phone at 314-305-5109.

Sincerely,



Amber Malcolm, MSN, RN, ACNP-BC

ALS Nurse Practitioner
Washington University School of Medicine
Department of Neurology/ Neuromuscular Division
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EXHIBIT D